CHAPTER 1

Introduction

Background and Significance of the Research Problem

Hospitalization of a child in a pediatric intensive care unit (PICU) is a life-threatening condition and an extremely stressful situation affecting both children and their family. In the United Kingdom, there are 59,696 pediatric intensive care admissions aged under 16 years in 2013-2015 (Paediatric Intensive Care Audit Network, 2016). In Thailand, approximately 10% of all pediatric patients are admitted to a PICU (Stawon, 2002) and their ages ranged from 1 month to 15 years. At Ramathibodi Hospital, the incidence of critically ill children in the PICU in 2015 and in 2016 were 545 (12.24% of all hospitalized children) and 558 (11.95% of all hospitalized children) cases respectively (Ramathibodi Hospital Statistics, 2017). At Maharaj Nakorn Chiang Mai Hospital in 2015 and in 2016, 387 (8.00% of all hospitalized children) and 507 (10.04% of all hospitalized children) cases of critically ill children were admitted to PICU (Maharaj Nakorn Chiang Mai Hospital Statistics, 2017).

Critically ill children who are admitted to a PICU have different underlying diseases affecting vital body systems. The most common problems include respiratory problems, cardiovascular problems, neurological problems, renal problems, gastrointestinal problems, hematology and oncology problems, septic shock, and post-operative complications (Bayrakci et al., 2014; Slota, 2006). They are admitted to a PICU from the condition of respiratory failure, cardiac failure, and etc. Thus, they require advanced treatment and intensive care consisting of continuous and closed monitoring of their clinical symptoms to stabilize the condition. Most children usually undergo various invasive procedures such as endotracheal intubation, central venous catheterization, urinary catheterization, and thoracic catheterization (Carnevale & Gaudreault, 2013). Generally, a child in PICU is confronted with tremendous suffering in all physical, psychological, and social aspects. Physically, a child is usually exposed to discomforts and pain caused by the disease, treatments, and

various procedures to save life such as invasive procedures, endotracheal suctioning, intravenous fluid and medication administration (Carnevale & Gaudreault, 2013). Moreover, the child may suffer from the unfamiliar PICU environments in terms of light, sound, and uncomfortable beds, resulting in discomfort and sleep disturbance (Carnevale & Gaudreault, 2013; Kudchadkar, Aljohani, & Punjabi, 2014). Therefore, the child hospitalized in PICU is more likely to have high stress that requires warm support from the parents.

With serious physical and psychological conditions of the child in PICU, most parents and/or family caregivers were often shocked by the perception that a child may be in a near-death situation. This certainly caused them to develop severe psychological stress (Shudy et al., 2006). In addition, previous studies indicated that sources of parental stress were the surrounding lights and sounds (Board & Ryan-Wenger, 2003; Carter, Miles, Buford, & Hassanein, 1985; Kumar & Avabratha, 2015), the child's appearance, the child's behaviors and emotional reactions (Carter et al., 1985; Lee, Lee, Rankin, Alkon, & Weiss, 2005; Miles & Carter, 1982), the invasive medical procedures (Board & Ryan-Wenger, 2003), the staff's communication and behaviors (Carter et al., 1985), the separation from the child (Aldridge, 2005; Carter et al., 1985), and changed parental roles (Aamir, Mittal, Kaushik, Kashyap, & Kaur, 2014; Carter et al., 1985). Having a child in PICU also affects parents in terms of a change in other roles, a decrease in their social participation, financial stress, and job loss (Jintrawet, 2005; Shudy et al., 2006). Most parents need to pay attention to and take care of their hospitalized child with life-threatening illness while they still need to take care of the other children and family members (Jintrawet, 2005; Shudy et al., 2006). Additionally, the parents also need to perform other roles at the same time. This will cause them to be unable to effectively perform other roles. Also, some parents express alteration of the marital relationship and divorce occurring after their child is admitted in PICU (Shudy et al., 2006). Some parents have decreased social participation and a change in relationships with others such as friends, relatives, and neighbors (Sawatzky & Fowler-Kerry, 2003; Shudy et al., 2006). Similarly, a finding of Jintrawet (2005) showed that some parents had to leave their job, lost income and had increased living expenses while their child was hospitalized in PICU. Therefore, hospitalization of a critically ill child in PICU has been identified as a tragedy and stressful experience to parents and/or family caregivers. Some parents showed negative responses, including anxiety (Colville, Darkins, Hesketh, Bennett, Alcock, &

Noyes, 2009), depression (Busse, Stromgren, Thorngate, & Thomas, 2013), helplessness (Aamir et al., 2014), feelings of uncertainty (Latour et al., 2011), fear, and guilt (Aamir et al., 2014; Colville et al., 2009).

Psychological well-being is defined as a state of individuals' positive and negative feeling towards their current life situations (Dupuy, 1984). There are six components of psychological well-being, including anxiety, depression, general health, positive well-being, self-control, and vitality (Dupuy, 1984). Considering human as a holistic being consisting of physio-psycho-socio cultural developmental and spiritual aspects, decreased psychological well-being can affect of the life aspects and results in an unstable state. The persons with compromised psychological well-being will no longer be sound. Parents with decreased psychological well-being are certainly not in well-being state and if this persists for a long time, it will affect the parent's health (Lee, Lee, Rankin, Weiss, & Alkon, 2007). The reduced psychological well-being has an impact on physical well-being of parents, and causes many symptoms such as headache, fatigue, low energy, sleep disturbance, and eating disturbance (Busse et al., 2013; Shudy et al., 2006). Lee and Kimble (2009) reported sleep disturbance in mothers of infants hospitalized in the NICU, including average nighttime sleep duration of less than seven hours/night, raised fatigue and diminished well-being. Declining health state of parents can affect their ability in child care involved. The compromised psychological well-being of parents also affect the ill child's well-being. The parent with high anxiety or stress are conductive to less attention, perception and learning, leading to poor child care as well as poor parental role performance. Not only the ill child will be affected but also other well child will be suffered from the parents' unwell state. The other child in the family may fell being abandoned leading to poor sibling a relationship and family conflict (Miles & Carter, 1982; Shudy et al., 2006). On the contrary, high psychological well-being affects parents and child positively. The parents will be able to cope well with the problems encountered and participate in caring (Melnyk et al., 2004; Mirghafourvand et al., 2017) leading to faster recovery of child's health and reduced length of stay (Gonya, Martin, McClead, Nelin, & Shepherd, 2014). Therefore, psychological well-being of parents is a very important concept that healthcare providers should concern and sustain its optimal state.

In order to effectively enhance the parents' optimal psychological well-being, healthcare providers need sufficient information and understanding of their psychological well-being state and its influencing factors. Unfortunately, there is little existing knowledge regarding psychological well-being level of Thai parents whose child was hospitalized in PICU as well as its associates. From literature review, only one study in Thailand that reported the bivariate relationship between a few selected factors including parents' education, uncertainty in illness, emotional focused coping, and well-being ($r = .32, -.55, -.46$, respectively, $p < .01$) (Vrolarn, 1992). Other variables may actually also be related to psychological well-being but have never been examined before. As psychological well-being of parents is the outcome of stress, it may explained by stress process as proposed in the Stress Process Model (SPM) (Pearlin, Mullan, Lieberman, & Mullan, 1990). The SPM is often used to describe the psychological state of caregivers of patient with many chronic illnesses, even though it was established for caregivers of Alzheimer's patients (Menne, 2006). The model consists of four components 1) the background and context of stress, 2) the stressors, 3) mediators of stress (or the moderating resources), and 4) the outcomes of stress. Based on the SPM, psychological well-being is the outcome of the stress process happening when the parents encounter the stressful situation that is the child's serious illness in PICU. Parents' psychological well-being may be associated with the parent's characteristics, particularly religious belief; stressors in PICU that include the child's behavior and emotional responses; and the moderating resources including coping, social support, and sense of coherence.

The child's behavioral and emotional responses are considered as primary stressors to the parents. The behaviors include the child's physical and emotional responses to pain, discomfort or other critical states, including crying, frightening, restlessness, demanding behavior, acting or looking as if in pain, uncooperativeness, inability to talk or cry, anger, and sadness. These behaviors are found to be related to parental stress that reflects their psychological well-being during their child's admission in PICU (Miles & Carter, 1982; Nizam & Norzila, 2001). A previous study also showed that the perceived child's behavior and emotional responses were positively correlated with negative psychological states such as anxiety ($r = .62, p < .01$) and depression ($r = .37, p < .05$) among parents with a critically ill child in PICU (Busse et al., 2013).

Sense of coherence (SOC) is another potential factor influencing psychological well-being of parents. Sense of coherence is defined as "the individual's perception to a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that 1) the stimuli, deriving from ones internal and external environment in the course of living are structured, predictable and explicable; 2) the resources are available for one to meet the demands posed by these stimuli; 3) these demands are challenges, worthy of investment and engagement" (Antonovsky, 1987). The persons with a strong sense of coherence may appraise a stressful situation as non-stressful, and also help them better adapt or cope with their stressors (Antonovsky, 1987). Moreover, in the SPM, sense of coherence is classified as a mediating factor of coping with stress in a variety of population. Two previous studies found that sense of coherence was negatively correlated with stress and depression among mothers of child with autism ($r = -.61$, $p < .001$) (Mak et al., 2007) and mother of child with intellectual disability ($r = -.72$, $p < .01$) (Olsson & Hwang, 2002). One previous study also showed that sense of coherence significantly influenced psychological well-being of caregivers of stroke victims ($r = .31$, $p < .01$) (Forsberg-Warleby et al., 2002).

Coping is one of the factors that may influence psychological well-being of parents in PICU. Lazarus and Folkman (1984) defined coping as "a constantly changing cognitive and behavioral effort to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." Moreover, Pearlin and colleagues (1990) stated that coping was the mediator or the buffer against stressors through direct and indirect pathways in the SPM. To cope with stressors in PICU, a prior study showed that all parents used a combination of both problem-focused and emotion-focused approaches in order to feel well (LaMontagne & Pawlak, 1990).

Religious belief is another variable founded to relate to psychological well-being. In SPM, religious belief is the parents' characteristic that can affect psychological well-being. Religious belief is the fundamental level of religion and a set of ideological commitments, acceptance, and trust to any religions (Joshi & Kumari, 2011). Moreover, Koenig (2007) proposed that the emotional suffering caused by loss or change may be diminished through religious beliefs or practices. Additionally, the previous study by Kaliampos and Roussi (2015) suggested that there were trends indicating that religious belief negatively predicted

psychological distress in subgroups of Greek cancer patients such as stage IV cancer patients and patients who did not undergo surgery.

Considering social support, it is a multidimensional concept. Schaefer, Coyne, and Lazarus (1981) viewed social support as available assistance from others, including emotional, tangible, and informational support. Emotional support includes intimacy and attachment, reassurance, and being able to rely on and confide in a person. Tangible support involves direct help or service such as money, goods, loans or gifts, and talking care of someone. Informational support includes providing advice, information, and feedback. The parents may receive support from family, friends, and health care providers. In the SPM, the social support is also classified as a mediator that helps persons cope with stress thereby increasing psychological well-being (Pearlin et al., 1990). From the previous studies, Chappell and Reid (2002) found a positive relationship between perceived social support and well-being of caregivers with neuro cognitive disorders ($r = .34$, $p < .01$). In children with chronic illness, the findings of Boonyawat and Sunsern (2005) showed a positive relationship between social support and well-being of Thalassemic children's caregivers ($r = .48$, $p < .05$). Furthermore, informational and emotional social support from health care providers was important in improving psychological well-being and reducing anxiety of parents whose child was being admitted to the PICU (Aksornsri et al., 2012; Beheshtipour et al., 2014).

Based on the aforementioned literature review, psychological well-being of parents and caregivers is one of the essential goals of acute and chronic care nursing, and is worth receiving attention. Previously, most studies explored some discrete partial aspects of psychological problems of parents, such as anxiety, stress, and depression (Aamir et al., 2014; Kautrakool, 2005; Lee et al., 2007; Pooni et al., 2013). There was little existing knowledge regarding factors predicting psychological well-being of parents of a critically ill child. The present study was designed to explore the level of psychological well-being and its predicting factors among parents of a critically ill child in PICU. Knowledge gained from this study is crucial to the planning of effective nursing intervention to enhance parents' psychological well-being that contributes to great parent participation in caring and transmits to the well-being of their child hospitalized with critical illness. Furthermore, the

findings of this study will be significant for developing further research in family caregivers of a critically ill child.

Research Objectives

The objectives of the present study were as follows:

1. To describe the levels of psychological well-being among parents of a critically ill child in the PICU.

2. To examine the relationships between the child's behavioral and emotional responses, sense of coherence, coping, religious belief, social support, and psychological well-being among parents of a critically ill child in the PICU.

3. To identify the ability of the child's behavioral and emotional responses, sense of coherence, coping, religious belief, and social support in predicting psychological well-being among parents of a critically ill child in the PICU.

Research Questions

The research questions of the present study were as follows:

1. What is the psychological well-being level among parents of a critically ill child in the PICU?

2. What are the relationships between the child's behavioral and emotional responses, sense of coherence, coping, religious belief, social support, and psychological well-being among parents of a critically ill child in the PICU?

3. How much of the variability in psychological well-being among parents of a critically ill child can be explained by the child's behavioral and emotional responses, sense of coherence, coping, religious belief, and social support?

Research Hypotheses

1. The child's behavioral and emotional responses were negatively related to psychological well-being among parents of a critically ill child in the PICU whereas sense of coherence, coping, religious belief, and social support were positively related to psychological well-being among parents of a critically ill child in the PICU.

2. The child's behavioral and emotional responses, sense of coherence, coping, religious belief, and social support could predict psychological well-being among parents of a critically ill child in the PICU.

Definition of Terms

Parents of a critically ill child refers to the mothers or fathers of a critically ill child who are primary caregivers of their child hospitalized in PICU of tertiary hospitals.

Psychological well-being refers to parents' perception about a positive and negative feeling of parents experience on their current life situations that relates to their critically ill child hospitalized in PICU. It was measured using the Psychological General Well-Being Index (PGWBI) of Dupuy (1984) translated into Thai by Mapi Research Trust.

The child's behavioral and emotional responses refers to the child's physical and emotional responses as perceived by parents while the child is hospitalized in PICU, including crying, frightening, restlessness, demanding behavior, acting or looking as if in pain, uncooperativeness, inability to talk or cry, anger, and sadness. It was measured using Child's Behavioral and Emotional Responses Scale of Carter and Miles (1989) that was translated into Thai by the researcher.

Sense of coherence refers to the parents' perception to global orientation that expresses the extent to which they have a pervasive, enduring though dynamic feeling of confidence that 1) the stimuli, deriving from their internal and external environment in the course of living, are structured, predictable and explicable (comprehensibility); 2) the resources are available to them to meet the demands posed by these stimuli (manageability); 3) these demands are challenges, worthy of investment and engagement (meaningfulness). It was measured using the Sense of Coherence Scale–Short Form (SOC-13), Thai Version translated into Thai by Hanucharurnkul, Intarasombut, and Putawatana (1989).

Coping refers to the parents' constantly changing cognitive and behavioral efforts to manage stressful situations caused by hospitalization of their critically ill child in PICU. It was measured using the Jalowiec Coping Scale (1988) translated into Thai by Mingkwan and colleagues (1999).

Religious belief refers to the mental representation of parents' attitude positively oriented towards Buddha and the Buddhist doctrine as being true, particularly one without proof, including belief in 1) the four components of saddhā that include a belief in kamma or accordance with the law of action (kamma-saddhā), a belief in the consequences of actions (vipāka-saddhā), a belief in the individual ownership of action (kammassakatā-saddhā), and a belief in the enlightenment of the Buddha (tathāgatabodhi-saddhā); 2) the three characteristics of existence that include impermanent (aniccā), suffering (dukkha), and impersonal or not-self (anattā). It was measured using the Buddhist Belief Questionnaire developed by the researcher.

Social support refers to the parents' perception of available helps from family, friends and health care providers to promote their psychological well-being during hospitalization of their critically ill child in a PICU. The available support resources include emotional support, informational support, and tangible support. It was measured using the Modified Version of Social Support Questionnaire, Thai Version developed by Schaefer, Coyne, and Lazarus (1981), that was translated and modified to be used with Thais by Hanucharurnkul (1988)